HHS Public Access

Author manuscript

Prog Community Health Partnersh. Author manuscript; available in PMC 2015 September 14.

Published in final edited form as:

Prog Community Health Partnersh. 2013 ; 7(2): 153–161. doi:10.1353/cpr.2013.0019.

Assessing Follow-up Care After Prostate-Specific Antigen Elevation in American Indian/Alaska Native Men: A Partnership Approach

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Abstract

Background—Although many studies conducted among American Indian and Alaska Native (AI/AN) populations may help to advance medical science and lead to improvements in health and health care, historically few have endeavored to share their findings, benefits, and/or expected outcomes with the communities in which they are conducted. This perceived lack of responsiveness has contributed to a perception in some AI/AN communities that researchers are disrespectful and may not make community needs a priority.

Objectives—In the context of a study assessing the care received by AI/AN men with incident elevated prostate-specific antigen (PSA) levels, this paper describes our experience building collaborative relationships, planning, conducting analyses, and disseminating findings with four AI/AN communities.

Methods—We established formal partnerships with three Northern Plains AI communities and one AN tribal health organization, convened a 12-member Community Advisory Board (CAB), and obtained study approvals from all necessary tribal and institutional review bodies before implementing our study. A menu of options for study implementation was given to key collaborators at each site. CAB members and collaborating tribes contributed to each phase of the study. After data analysis, results were shared with tribal and institutional leaders.

Lessons Learned—Face-to-face communication, flexibility, and adaptability, as well as clearly defined, respectful roles contributed to the success of the study on the part of both the researchers and community partners.

Conclusions—This study demonstrates the importance and feasibility of forging collaborative relationships with AI/AN community leaders in regions of Alaska and the Northern Plains in cancer control initiatives for AI/AN men.

Keywords

Community-based participatory research; community health partnerships; urogenital neoplasms; health care quality and access

Past research involving Native American communities has been promoted as an effort to improve health status.[1] However, despite cooperation and participation in research studies, AI/AN people have continued to have significant health disparities and negative feelings about past research.[1–6] Historically, although many studies conducted in these populations may have helped to advance medical science and aimed to eventually improve health and health care, few have endeavored to share their findings, benefits, and/or expected outcomes with the AI/AN communities in which they were conducted.[1,7] This perceived lack of responsiveness to community concerns has contributed to negative perceptions of research in some AI/AN communities. Unethical research practices and misuse of participant information and data have further contributed to a generalized distrust of research in many Native communities.[8]

Community-based participatory research (CBPR) has been endorsed by AI/AN advocates, tribal leaders, and researchers[9,10] as an approach that honors community priorities and engages community representatives as equal partners in all aspects of the research process, from defining the research question to the interpretation and dissemination of research results.[1,7] CBPR also has been implemented as a means of developing local research capacity and increased local ownership of health and health care problems and their solutions.[11]

In late 2007 and early 2008, the U.S. Centers for Disease Control and Prevention (CDC) initiated a Request for Applications (RFA 2008-R-15) through the Potential Extramural Project program. Concerned about health disparities, researchers at the CDC wanted to assess the feasibility of a study that would identify AI/AN men with elevated PSA levels and document the patterns of diagnosis and clinical follow-up for the affected men. Because of the extant literature, it was clear that a CBPR approach would be a desirable methodology for this activity. The RFA also required a dissemination plan for translation of results back to communities.

Mayo Clinic’s relationships with AI/AN tribes and organizations extend back to collaborations in Alaska that began in 1963 (Anne Lanier, personal communication), and to formal outreach, training, education, and infrastructure development programs,[12–14] focusing in the Northern Plains that began in the mid-1990s.[15,16] These programs originally launched when tribes in the Aberdeen Indian Health Service (IHS) Area requested assistance in developing breast and cervical cancer screening programs.

In 2006, Mayo Clinic and the Department of Health and Human Services/IHS signed a memorandum of understanding (MOU). The MOU addressed five areas designed to improve

tribal health: Cost-effective health care, research, education, grants and funding, and professional development, and intended that all initiatives reflect partnership and mutual benefit.

In this context, and around the same time as the CDC RFA was issued, several tribal organizations with which our team had established relationships had identified men's cancer issues as an unaddressed need. A team from Mayo Clinic regularly attends standing meetings of the Minnesota tribal health directors and actively collaborates with the Alaska Native Medical Center. When the research opportunity arose, we initiated a conversation with several tribal health and IHS leaders to inform them of the opportunity to launch a collaborative, federally funded assessment of prostate care in their clinics and hospitals and invited tribes who were interested to discuss their level of interest further with us. Several representatives expressed interest. Most were motivated by a desire to demonstrate they were pursuing men's health issues in their communities and saw participating in this project as a tangible means of achieving that objective. Of the original six communities who expressed an interest, four went on to partner with us once funding was obtained and as the study commenced. Both the CDC and the tribal representatives wanted to use CBPR principles pragmatically to optimize the possibility of sustained community empowerment and change occurring even from a small, retrospective study.

In a context of cultivating strong, trusting, working relationships, we worked with our partners and CAB to design and carry out a study that captured theoretically and practically the essence of the CBPR definition: "a collaborative approach that equitably involves … community members, organizational representatives, and researchers in all aspects of the research process."[11] Whereas the primary CDC objective was to assess the feasibility of conducting a CBPR-based study involving AI/AN communities and to describe patterns of care after a newly elevated PSA, we also sought to respond to the needs and interests of tribal community priorities. Herein, we have described our experience in planning and conducting these analyses and disseminating results to community partners.

METHODS

Consistent with the CDC objectives, we and our partners established three specific aims related to the patterns of follow-up care received by AI/AN men who had an incident PSA elevation at some point between January 1, 2006, and May 31, 2009: (1) Describe demographic, clinical, and service use characteristics, (2) assess patient-report experiences and outcomes of care, and (3) Identify "lessons learned."

Formation of Community Partnerships

After preliminary contact with tribal health directors and other key stakeholders at several locations in Minnesota and one in Alaska, we ultimately established formal partnerships with three Northern Plains AI communities and one AN tribal health organization. In numerous subsequent conversations, both in person and over the phone, we jointly discerned how best to fit the draft research objectives and proposed timelines (which originated with the CDC and Mayo Clinic) with the practical needs and limitations of the communities in

which the study would be conducted. A brief overview of our community partnership process is shown in Figure 1.

The formation and initial meeting of our 12-member CAB was an important first step in this process, both as a means of gathering representatives from each community under one roof and setting a tone of collegiality and teamwork that we hoped would facilitate frank discussion among partnering community members, health care providers, and academic researchers. Topics in our discussions included potential barriers to study implementation, suggested ways to overcome those barriers, and ideas about which issues related to an elevated PSA test and follow-up care among AI/AN populations were most relevant and important to address in the study. After this first face-to-face meeting, our research team sent electronic updates to CAB members on study progress at regular intervals. This initial feedback was supplemented with on-site visits to each of our partnering facilities to ascertain their specific needs and preferences regarding sampling, methodology, personnel, and research approval.

Obtaining Study Approval in AI/AN Communities

To conduct research within tribal entities, investigators must navigate review processes that vary with the tribal organization, but can include review by tribal councils (which have many different configurations from a sole “executive branch” to a three-branch governmental structure), tribal or IHS institutional review boards (IRBs), tribal health departments, and various committees. In some instances separate MOUs must be drafted and signed. In nearly all cases, investigators must obtain tribal resolutions authorizing the research in addition to IRB approval from their academic institution. If research involves an IHS facility, staff, or patients, the investigators must also obtain reviews by area and national IHS review boards. Researchers who engage tribes must incorporate substantial time in their planning and study implementation for obtaining the necessary approvals and designing collaborative processes into their study protocols.

Before study implementation and while initial conversations were being held with community partners, we began obtaining the required IRB and/or tribal approvals from partnering sites and other relevant institutions such as the National IHS IRB. Approval was first sought and granted by the Mayo Clinic IRB. Protocols for the Mayo and National IHS IRBs were written generally to allow us flexibility to account for varied tribal expectations, requirements, and capacities for participation.

These tribe-specific characteristics impacted both how the study would be implemented and data collected, leading to study protocols specific to the circumstances in each of our four partnering communities but within the constraints of IHS and Mayo Clinic IRB requirements. In two communities, no formal protocol submission was required because our project was introduced by their Tribal Health Director, discussed by the Tribal Council, and eventually approved for implementation by unanimous vote. Two other communities with formal tribal approval processes had specific application processes, one of which was multistep and required initial “concept proposal” approval by an institutional committee before protocol submission to their area IRB. Upon IRB approval, several other institutional and committee reviews and approvals were needed for study implementation to commence

at that particular site. Timing of each submission at this partnering site was important, because missing a deadline date for one tribal review committee could delay submission to another. Approximately 1 year was devoted to the approval process for the four sites.

Data Collection Approach

Participants at each of our three partnering sites in Northern Minnesota were enrolled members of tribes where on-reservation care was available, whereas participants in Alaska resided in a geographically defined region surrounding a medical center that provides comprehensive medical services for AI/AN people living in Alaska. Early in the implementation phase, we developed a flexible data collection process that reflected site resource capacity and preferences. In Alaska, we used a subcontract to pay research nurses and other staff at the partnering facility to conduct all facets of data collection—both medical record reviews and personal interviews. In Minnesota, we blended modes of data collection using members of the Mayo research team or on-site staff depending on interest and overall staff capacity. At these three sites, the Mayo Clinic team, in collaboration the Great Lakes Inter-Tribal Epidemiology Center, collected all medical record data with the assistance and oversight of local tribal medical records, clinical, and information technology staff.

Specific Aim 1—Reviewed medical records in our study came from men who were (1) receiving or had ever received care at one of the four partnering sites, (2) between the ages of 50 and 80 years (inclusive) at the time of the medical record search, and (3) had a documented PSA test result greater than or equal to 4.0 ng/mL[17–19] in laboratory databases. We further limited our cohort to those men whose PSA elevation was incident (i.e., no documented evidence of prior elevations) and occurred between January 1, 2006, and May 31, 2009.

We followed a similar methodological approach to Nepple and associates.[20] Given the largely indolent nature of prostate cancer, and adapting their approach to the care delivery context of AI/AN men,[20] we decided that follow-up care received at or before 90 days would be considered “timely.” Using electronic medical records and paper records when available, a team of two (in Alaska, research nurses on staff at the medical center) or three (in Minnesota, two members of the Mayo study team and one epidemiologist from the Great Lakes Inter-Tribal Epidemiology Center) medical record abstractors manually collected basic demographics, insurance status, veteran status, and patterns of care using a standard chart abstraction instrument designed for the study. This instrument was a Microsoft Access database that was developed in collaboration with a research nurse and computer programmer in Alaska. This research nurse, with extensive prior experience conducting medical record reviews, was one of the two abstractors assisting with medical record review in Alaska and therefore had a vested interest in creating a user-friendly, comprehensive tool.

Patterns of care information collected during the medical record review included the timing, frequency, and nature of medical appointments after the elevated PSA test (i.e., records of both in-house and outside referrals), modes of communication between patient and provider (where present), the presence of comorbidities (only those used in Charlson index[21]

calculations), and treatments and/or medications prescribed in response to the PSA elevation. We also ascertained the primary indication for performing the PSA test: (1) Screening test for prostate cancer, (2) lower urinary symptoms, or (3) use within the context of prevalent benign prostatic hyperplasia or acute prostatitis. All data were double-entered into the Microsoft Access database. Any discrepancies between information recorded by the data abstractors were resolved by consensus or, if necessary, a third-party clinician adjudicated by consulting the medical record.

Specific Aim 2—For the second aim of the study, we developed a semistructured interview guide designed to examine key dimensions of men's experience related to follow-up care after elevated PSA, including general health, prostate care, mediators (including processes), doctor and patient roles, trust in medical profession, outcomes (e.g., quality of life/satisfaction), barriers, personal circumstance, institutional conditions, and demographics. The domains of doctor and patient role and trust in the medical profession were administered in a closed-ended fashion using existing survey measures.

With the same list of eligible patients used for the medical record review, staff at each of our collaborating sites contacted (by phone at Minnesota sites; in the clinic at Alaska) each eligible patient, inviting them to participate in an interview. A modest cash incentive was set ($25–$50) and offered by each site to defray time and travel expenses. Even when the Mayo Clinic team was asked to play a strong role in study implementation, we sought to build capacity and, where possible, train on-site staff for the role of interviewer. Two Minnesota partnering sites elected to have staff from the Mayo Clinic team conduct interviews and one opted to use local staff trained by members of the Mayo team. On-site interviewers were also trained by Mayo staff in Alaska.

On-site staff attempted to obtain interviews from all eligible men, contacting them up to three times. Interviews were audio-recorded and followed the script of the interview guide. To ensure confidentiality, audio files were stored on a secure electronic server at Mayo Clinic and were transcribed anonymously by a trained transcriptionist. Transcriptions were proofread and de-identified before analysis.

Data Analysis and Interpretation

Once all data from the medical record review and interview portions of the study had been collected, de-identified, and analyzed, we approached our primary contacts at each partnering site to discuss refinements to our data analysis approach and establish next steps for disseminating preliminary results to tribal leadership. Key contacts at each partnering site determined the venue, presentation format, and audience. Preliminary results were returned via brief, face-to-face, informal presentations in the fall of 2010 with tribal health leaders at each of our partnering sites. In September 2010, we also presented preliminary descriptive results to members of our CAB. From this session and other meetings with tribal partners, we were able to further refine our analyses.

When data analyses were complete (summer/fall of 2011), Mayo staff re-contacted tribal health leaders and collaborators in Minnesota and Alaska to ascertain their preferred mode of learning about study findings. At two of three Minnesota sites, Mayo study team

members gave formal, in-person presentations to tribal health leaders. At all Minnesota sites, the Mayo study team sent a one-page article summarizing the study's purpose, findings, and implications for the future, and encouraged collaborators to disseminate the document in community newspapers or clinic newsletters as they deemed appropriate. Out of these relationships, we were also invited to return to one clinic to conduct a professional development workshop in September of 2011 on screening for prostate cancer. We also provided each of our collaborators with an executive summary document detailing study findings specific to their site. In Alaska, Mayo staff presented a summarized version of results particularly related to study aim 1 at a medical grand rounds lecture. We continue to be in contact with these communities and are actively considering collaborative research projects even more focused on men's health priorities.

LESSONS LEARNED

In the process of conducting this pilot study, our research team learned a number of important lessons about conducting research in a unique community-based context involving sovereign tribal governments, many of which are similar to those listed in Burhansstipanov and colleagues.[1] In their work, Burhansstipanov and colleagues outline eight lessons learned while utilizing a CBPR approach to research conducted in tribal communities. Of those, "invest time to create the partnership" (lesson one), "create partnerships with leaders who have decision-making responsibilities from each organization" (lesson three), "implement active, effective communication among all CBPR partners" (lesson five), and "modify standardized evaluation procedures to be culturally acceptable and respectful of the local community" (lesson seven) especially resonated with our experience and the resulting lessons learned. For our study, we grouped these lessons into the overriding categories of communication and flexibility, roles and responsibilities, and challenges and limitations.

Communication and Flexibility

Among the many lessons learned throughout our process of study development and implementation, perhaps the greatest related to several aspects of communication and maintaining flexibility in our approach. We briefly describe several specific lessons learned pertaining to these areas.

First, there is no substitute for face-to-face interaction. No other mode of communication was as efficient and effective a means of fostering fruitful conversations about study-related details and maintaining momentum for the project. In some cases, email was the simplest and fastest mode of communicating with collaborators to assess study progress—particularly CAB members, most of whom reside and work in geographically distant locations. However, we found that taking the time to travel to partnering sites, meet face to face with individuals who were assisting with study implementation, and personally interact with partners provided the needed impetus for accomplishing study goals. It also helped the researchers to better understand the context in which prostate follow-up care was taking place and enabled community partners to participate directly in the research process.

Second, implementing this study required flexibility and adaptability on the part of both researchers and community partners. Researchers learned to adapt their approach to fit the

environment in which data collection was taking place. In our study, this played out in our development of a "menu" of options that allowed partnering sites to decide how they wanted to implement the interview aim of our study, described in subsequent paragraphs below. Flexibility and adaptability were also important characteristics of community partners, who were working with "outsiders" unfamiliar with their systems and who were also likely to have other competing priorities, which may have limited the amount of time and degree of assistance they could provide to researchers. At one study site, for example, we faced the challenge of recruiting an individual to assist with participant interviews, which meant time away from the employee's "regular" work. This employee's supervisor was amenable to his involvement, however, noting the experience would benefit the employee, the study, the organization, and the community as a whole.

Discussions among CAB members at our initial meeting proved invaluable in our process of discerning how best to design the study in a sufficiently flexible and respectful manner given the differences in environment, staffing, resources, and priorities of our partners. This was particularly true in discussions surrounding aim 2 of the study in which we proposed to gather patient-reported data about men's experiences after their newly elevated PSA. Engaging in extended discussions about the most appropriate means of implementing study aim 2 was crucial to its ultimate success.

At the suggestion of CAB members, we ultimately incorporated a "menu" of these and similar options for study implementation into our study protocol. This menu included a table of options with their associated pros and cons in the following topic areas: (1) What modes of data collection should be used? (in-depth interview, focus groups, or a survey); (2) where should these data be collected? (at the clinic, in the home, over the telephone, at a health fair); (3) who should collect the data? (Mayo research staff, Great Lakes Inter-Tribal Epidemiology Center staff; AI/AN research interns, staff on site, students from the University of Minnesota—Duluth); (4) how should eligible participants be identified? (generate list from electronic medical records, convenience sample); and (5) how should eligible participants be invited to participate? (mailing and/or phone call from study team, mailing and/or phone call from study site, posters, recruit from in-clinic appointment lists).

This menu of options was incorporated into study protocols at each partnering site. It was also used to initiate conversations with key contacts at those sites as phone calls and face-to-face meetings were scheduled to finalize details of study implementation. In our experience, using menus provided the right balance of concrete specificity to which a busy health director could react while preserving tribal control over study implementation. Menus also illustrate the broader lessons related to flexibility and adaptability that proved necessary to maintain project momentum and progress.

Roles and Responsibilities

Conducting CBPR in AI/AN communities may mean tribal partners choose to take an active role in all phases of the study or delegate to researchers the primary responsibility for executing the study. We came to appreciate both the benefits and challenges of varied levels of tribal involvement. The process of data collection can be facilitated and smoothed when local members are involved, but if a tribe is small or community members (including local

study staff) are well known to each other, potential privacy and confidentiality concerns can arise. Tribal partners may opt to have the outside researchers collect all data, as was the case in three of our four partnering communities, a preference that preserved participant anonymity and diminished the perception that personal health information of participating men might be revealed. This approach raises other challenges related to capacity building (e.g., a less empowered role of local partners may translate into less potential research personnel capacity), but is ultimately responsive to a tribe's sovereignty and community members' concerns over privacy and confidentiality.

Throughout the study, the research team was constantly reminded that tribal representatives work for their people and not for the researchers. This meant that timelines and implementation plans may need to be negotiated, but they were ultimately under tribal control. Delays in study implementation may also occur as tribal priorities are considered by authorizing bodies. This reality called for researchers to anticipate delays and identify personnel who could either predict which tribal processes might lead to delays or otherwise facilitate forward progression of the project. In this respect, flexibility combined with persistence characterized successful phases of study implementation.

Notwithstanding these concerns, in our experience, once a tribal commitment to research was made, it was honored. It was therefore essential that researchers respectfully reciprocate with the same level of commitment and follow through with disseminating study findings once analyses concluded. A violation of that trust would not only harm the current project but jeopardize future collaborations, harm institutional reputations, and exacerbate, rather than minimize, health disparities. In summary, working with tribes requires researchers to work alongside tribal representatives, maintain open lines of communication, and be adaptable in their approach.

Challenges and Limitations

We were able to complete our study in a manner that met the objectives of the funding agency and was simultaneously responsive to partnering site concerns. Doing so, however, was no small task. As would be the case with any community-based study, we encountered numerous challenges throughout the processes of study implementation, data collection, data analysis, and interpretation and dissemination of findings. Unique to this work, however, was the approval process.

Obtaining the required approvals from appropriate tribal research review bodies was a complex process. Each of our community partners had its own review processes and requirements—some with their own formal IRBs, others without, some with multiple review committees, and all with their own unique standards for protocol formatting. Although navigating these complex research approval processes was challenging, the process itself helped to forge stronger relationships among the collaborators. It also prompted careful thought with our community partners about how best to fit the study to the unique environments of each community.

Importantly, researchers working with tribal communities must realize that the comprehensive nature of research approvals in many AI/AN communities has arisen out of

historical missteps on the part of researchers less considerate of AI/AN communities. Although specifically responsible for human research protections, the primary obligation of IRBs is to ensure human subject protection through compliance with federal regulations and the principles of Belmont.[22] There are no federal protections for groups or communities, no oversight of data ownership agreements, and no assurance that research conducted will benefit AI/AN people without formal policies under which research may take place in AI/AN communities. Although some IRBs incorporate these policies within their domain, others do not and, in some cases, tribal leaders have assumed a direct role oversight. Although complex and occasionally time consuming, tribal review and approval provides oversight in addition to facilitating researcher access to local communities.

Because our research team was committed to maintaining regular personal contact with collaborators at partnering sites and was also responsible for data collection via medical record review and personal interviews, travel was a necessary, but often logistically challenging and time-consuming component of this study. For those partnering sites who chose to use on-site community members in conducting personal interviews with eligible men (as part of study aim 2), travel was also required to provide one-on-one instruction and interviewer training by members of our research team. Whether more liberal use of technology (i.e., video conferencing) would have been (or in the future could be) a suitable substitute for travel is unclear.

In addition to these larger strategic concerns, several logistical challenges also hampered research implementation. Much advanced planning and coordination were required to ensure that all interviews, once recorded and properly labeled, were either uploaded onto a secure file transfer protocol site accessible by both members of our research team and community partners or mailed to our research team in a timely manner so that transcription and data analysis could ensue. At one site, we also faced challenges in retaining study staff. When the initial interviewer who had volunteered to assist with study aim 2 unexpectedly left, we were faced with the task of identifying another suitable interviewer at that site as well as conducting additional on-site training once a replacement was identified. These challenges, although by no means unique to conducting research in AI/AN communities, highlight the degree of effort necessary to design and implement even a small, retrospective pilot study, especially when the study is conducted over great distances.

CONCLUSIONS

Overall, both the process of study implementation and the results of our study itself provide evidence of the importance and feasibility of conducting research in AI/AN populations and forging lasting, collaborative relationships with key members of these communities. In addition to providing some useful pilot data, this project was developed in the context of an existing, multi-year MOU between Mayo Clinic and the IHS that was responsive to needs and priorities of the IHS and tribes and related to other projects in both regions that were launched in response to tribal requests. Thus, the “finding” of a successful partnership between an academic medical center, several sovereign tribal organizations, the IHS, and the CDC may serve as a foundation upon which future collaborative projects can build to incorporate CBPR in a robust way. Funding agencies that promote CBPR projects must be

committed to encouraging new researchers to collaborate with tribes, but collaborate in ways that suit tribal priorities.[23]

We believe this study was an important first step in beginning to understand how care is delivered to AI/AN men with an elevated PSA as well as in keeping the door open to future conversations about this and other research priorities in AI/AN communities.

Acknowledgments

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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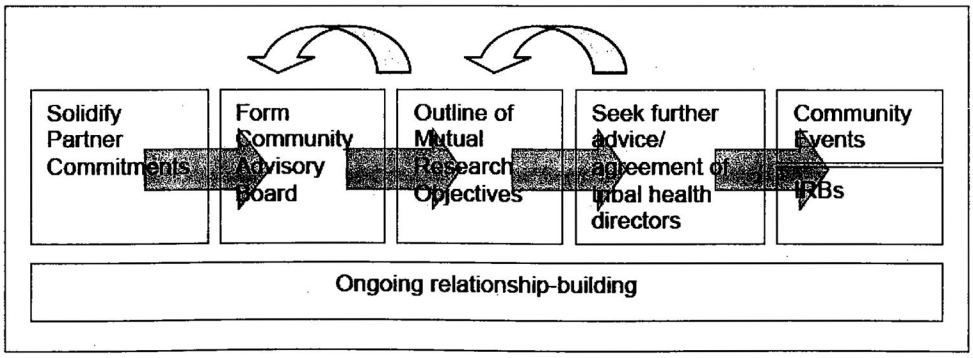

Figure 1.
Our Community Partnership Project Development Approach